Dr. Laurence R. Tancredi Kidney Disease Control Program National Center for Chromic Disease Control 4040 North Fairfax Drive Arlington, Virginia 22203

Re: KDC/PP

Dear Dr. Tancredi:

Your letter of October 16th arrived while I was on a rather long trip out of the country and I hasten to reply now that I have returned.

Many of the questions that you have brought up have been the subject of some discussions here at Stanford involving a number of members of the Schools of Medicine and Law and which will I believe be embodied in an article which is being drafted by Dean Bayless Manning of the Law School. I am taking the liberty of sending copies of this correspondence to him with the hope that he may be able to add to it.

The recent well publicized success in heart transplantation lends additional emphasis to the questions asked in your letter.

The Sunday, December 10 issue of the Washington Post, in its "Outlook" section will carry some comments I wrote that are quite pertinent to your questions.

The problem of a minor donor is a very thorny one since, in my view, it may be just as traumatic to a youngster's emotional development to be barred from helping save the life of a member of his family as it is to impose the obligation upon him. Clearly the consent of the legal guardians of the minor, as well as of the minor himself, must be invoked, but in addition to this, there should be a careful psychiatric consultation and continuing psychotherapeutic follow-up as the basis of making a decision and also for support regardless of which decision is in fact made. A possible alternative might be very general legislation explicitly barring minors from consenting to being donors, but I do not find very great justification for this in the light of existing medical knowledge about the magnitude of risks involved in donating this organ.

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The selection of recipients, it seems to me, poses much more difficult problems in view of the scarcity of the resource. The best I can come up with now is to suggest the minimum deviation from the existing norms for difficult surgery-mnamely that each potential recipient still have to work it out directly with a hospital or prospective surgeon whether he can win their interest in his case and that the ultimate responsibility will still be incumbent on the patient to find an acceptable donor. The best way of handling the resource allocation would be to organize mutual health clubs, the members of which promise to furnish a kidney if another member has exhausted the reasonable resources of his own immediate family after proving to have a severe indication for Individuals with already manifest kidney disease or otherwise displaying high risk would be obliged to enter with registrations of additional healthy individuals in order to participate. Prospective donors would then be selected first by lot and then by specific tissue matching, etc. for the purpose. This is roughly analogous to the provision of blood for transfusion purposes by organizations like the Community Blood Reserve in Palo Alto.

To start with, the club might consist almost entirely of relatives of high risk patients and even there this might be the best way to build up a cadre of potential donors for new patients that may come into the picture who do not have suitable relatives. As we get further along in the science of tissue typing, this kind of reciprocity will become much more meaningful.

I believe it would be extremely mischievous to set up any formal criteria to qualify individuals as being acceptable recipients in terms of the parameters stated in your Question 2 excepting the medical considerations.

The main comment I have on procuring kidneys from living donors is that such donors should be provided with an insurance policy for the risk of their life as part of the operative procedure of transplantation and also for any influence on their life expectancy coming from their having been deprived of one kidney. At the present time the cost of such insurance is a hidden subsidy on the part of the donor to the recipient. This may be inconsequential when the two belong to the same family, but I believe it should be a definite consideration and part of the apparatus of informed consent whether or not the donor is or is not in the same family. In the latter case the exchange of cost of the insurance may or may not be relevant. Some government subsidy for the organization and cost of such insurance

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should be considered. The existence of such an insurance system might well bypass some of the headaches we are bound to get into when a donor eventually dies from this so-called "safe" operation.

With respect to cadavers, we certainly will need some important improvements in the law particularly with respect to the form of will whereby organs can be dedicated. The normal form of testament is quite inadequate because of the need to bring a proposed "last will" to probate as a means of certifying that it had not been superceded by any later act of the decedent. I suggest that we go into something similar to automobile registration where the will of the decedent has been expressed by formal registration and remains binding on him and his legal representative unless a later change of registration has been filed and accepted by the responsible state agency. Such a procedure is slightly more cumbersome during the lifetime of the decedent but can eliminate confusion at a point when time is of the essence, namely in deciding whether the organ can be prepared for storage and later transplantation. Some protection for surgeons who act in good faith as against the possibility of fraud or misidentification of the decedent is also necessary.

As my commentary on Sunday indicates, I would be opposed to attempting to "redefine death" since this has numberless and unforeseen implications. Death has after all no significant biological meaning since the organism simply does not die all at once. Instead it should be possible to authorize very specific surgical interventions without regard to whether the patient is regarded as "dead" or "alive" under the assumption that death is imminent and certain other criteria for this are fulfilled. Again the maximum emphasis in implementing such an authorization should be placed on having secured the active consent of the doomed individual.

I am also taking the liberty of enclosing a brief bibliography that one of my assistants has compiled on the basis of a citation indexing search of some of the recent literature.

Sincerely,

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Joshua Lederberg Professor of Genetics

JH/lh

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